Mental Health Intellectual Disabilities: effective interventions and service models

Health services research and complex interventions

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Objectives

We will discuss

• why we need effective interventions
• What are complex interventions in applied research
• how to involve service users and other stakeholders in research
Mental disorders

- psychosis
- bipolar affective disorder
- common mental disorders
- dementia
- challenging behaviour
Health Services Research

• “Health Services Research” was formally recognised in 1966
• 1979, 1995, 2000
• Health services research is the multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of health care, and ultimately our health and well-being. Its research domains are individuals, families, organizations, institutions, communities, and populations.

Lohr & Steinwachs, 2002
(http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1430351/)
Hierarchy of evidence

- Systematic Reviews
- Randomized Controlled Trials
- Cohort Studies
- Case-Control Studies
- Case Series, Case Reports
- Editorials, Expert Opinion
Complex Interventions-1

- Widely used in health interventions and particularly relevant to mental health
- Definition:
  - Several interacting components
  - Challenges to delivering the intervention
  - Intervention may target a number of organisations or groups
  - Number and variability of outcomes
  - Degree of flexibility or tailoring of the intervention
• In reality, distinction between simple and complex interventions is blurred

• Two key questions when evaluating complex interventions:
  – Whether the intervention works in everyday practice
  – How does the intervention work?
    (what are the active ingredients? how are they exerting their effects?)
Key elements of the development and evaluation process

Development
1. Identifying the evidence base
2. Identifying/developing theory
3. Modelling process and outcomes

Feasibility/Piloting
1. Testing procedures
2. Estimating recruitment/retention
3. Determining sample size

Evaluation
1. Assessing effectiveness
2. Understanding Change process
3. Assessing cost-effectiveness

Implementation
1. Dissemination
2. Surveillance and monitoring
3. Long term follow up
Evidence based practice in intellectual disabilities

- Natural experiments
- Case control studies
- Expert opinion
- 5% of papers in AJIDD are about interventions
- Compare with cancer, heart surgery, other medical fields
1. Developing a complex Intervention

- Identify the evidence base: systematic review
- Identify and develop appropriate theory
- Modelling process and outcomes may identify weaknesses or a full scale evaluation is unwarranted
2a. Feasibility studies

- Feasibility study can be useful in estimating and identifying:
  - Willingness of participants to be randomised
  - Willingness of clinicians to recruit participants
  - Number of eligible participants/ recruitment rate
  - Standard deviation of the outcome measures needed in order to estimate the sample size
  - Characteristics of the outcome measure/ design a suitable outcome measure
  - Response rates to questionnaires, adherence/ compliance rates, follow up rates
2b. Pilot studies

- Smaller version of the main study
- Focuses on the processes to ensure recruitment, randomisation, treatment and follow up run smoothly
- Internal and external pilots
- May use qualitative methods, e.g. to understand barriers to participation
- A series of studies may be needed to refine the design
3. Assessing Effectiveness

- Always consider randomisation – most robust method of preventing selection bias
- Experimental approach may not be feasible in some cases: intervention is irreversible, applies to the whole population, large scale implementation is underway.

Then

- Consider observational study (cohort, case control design) or quasi-experimental design.
4. Pragmatic trials

– Compare the way treatments are actually delivered in clinical practice
– Test whether the treatment works overall in populations to which it is offered
– Have a design with high external validity and non restrictive inclusion criteria
– Need larger samples because of variation in treatment
5. Choosing outcomes and assessing cost effectiveness

- Ideally one primary outcome and a (small) number of secondary outcomes
- An economic evaluation should be included, if possible – more useful for decision makers.
<table>
<thead>
<tr>
<th>Type of economic evaluation</th>
<th>Cost measure</th>
<th>Types of consequences identified for alternatives</th>
<th>Method for measuring &amp; valuing consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost-minimisation analysis</td>
<td>£</td>
<td>Clinical, health, and non-health outcome need to be identical</td>
<td>None</td>
</tr>
</tbody>
</table>
| Cost-effectiveness analysis | £            | One clinical, health non-health outcome
Same measure for both alternatives but significant differences in outcomes | As per clinical measure                     |
| Cost-consequences analysis  | £            | Clinical, health, and non-health outcome | List consequences separate                  |
| Cost-benefit analysis       | £            | Single or multiple outcomes | £                                           |
| Cost-utility analysis       | £            | Single or multiple measures of quality of life | DALYs and QALYs gained                     |
Activity

- Intervention A is a behaviour therapy for people with learning disabilities and depression.
- What alternative intervention might you want to compare this with?
Feedback

Costs and consequences could be compared with one/more of the following:

- Doing nothing (i.e. not treating depression)
- Medication
- Alternative therapies e.g. light therapy, dance therapy

But

→ The choice of which option to implement would depend on the decision maker
6. Understanding process

- Provides insight into why an intervention worked or why it failed
- How? surveys/semi-structured interviews with clinicians and patients.
- Also: assessment of fidelity of treatment and quality of implementation, clarification of causal mechanisms and identification of factors associated with variation in outcomes
- How? Record/observe therapy sessions to assess fidelity
7. Implementation

• Getting evidence into practice: make evidence available using methods that are accessible and convincing to decision makers

• Surveillance, monitoring and long term outcomes: Consideration should be given to how rare or long term effects of the intervention can be measured e.g. through routine data sources and record linkage.
complex interventions quiz

- Are appropriate to use in ID
- Have many components
- Must only be randomised controlled trials
- May include a pilot phase
- Can not be used in pragmatic conditions
- May include an economic evaluation

- Recording and rating sessions is part of treatment fidelity
- Implementation of research findings is essential for evidence based practice
example
People with ID:

- Just as vulnerable to depression & anxiety as the general population

Four to six fold more likely to suffer from affective disorders (Richards et al, 2001; Maughan, 1999).

Prevalence rates (Cooper et al, 2007): 6.6 % affective & 3.8 % anxiety disorders
Psychotherapy & intellectual disabilities

- Historically an exclusion criterion for psychotherapy.
- “Therapeutic disdain” (Bender, 1993): therapists were reluctant to offer therapy.
- Mainly psychopharmacological or behavioural interventions.
- Treatment goals discussed with the carer rather than the client.

- **Simpson & Miller (2005):** A year’s psychodynamic orientated therapy with adults across the range of ID leads to positive outcomes in improving emotional intelligence.

- **Rulak et al, 1991 & Dush at al, 1989:** Work with children suggests that a mature cognitive function may not be necessary for an individual to make use of cognitive behaviour therapy (CBT).

- **Dagnan and Chadwick (1997):** People with mild to moderate ID are able to establish links between thoughts and feelings.

- **Kroese et al (1998):** Some tentative steps are been taken by CBT therapists interested in cognitive content to adapt their approaches to people with learning disabilities.
Skills required for CBT

– **Capacity to differentiate between feelings, thoughts & behaviour** (Sams et al, 2006)
  • Identification of behaviours & feelings is linked to verbal ability,
  • Identification of thoughts is associated with general IQ.

– **Correctly identify and label emotions** (Joyce et al 2006).

– **Link situations to emotions** but have difficulties linking beliefs, emotions, and situations (Dagnan et al 2000)

– People with mild ID **able to learn cognitive mediation** & generalise to new materials (Bruce et al 2010):
UK policy and practice

• **Valuing People (& VP Now) (2001 & 2009)**: a UK government white paper – same access to healthcare as people without disabilities.

• Increase access to psychological therapies

• **NICE (2002)**: Healthcare guidelines advocate CBT as a preferred & effective form of treatment for depression and anxiety disorders in the general population.
CBT: evidence in intellectual disabilities

- **Meta-analysis** (Prout & Nowak-Drabik, 2003)

- **Individual and group**

- **Success in treating**
  - Anger (Rose et al, 2000; Willner, 2004; Gulbenkoglu et al, 2006),
  - Psychosis (Kirkland, 2005),
  - OCD (Willner & Goody, 2006)
  - Anxiety (Lindsay et al, 1997)
  - Depression (Lindsay et al, 1993; McGillavary et al, 2008).
Manual Development for individual CBT
Modelling the intervention

Manual development

• Literature search
  – Health Databases
  – Intellectual Disabilities Journals
  – CBT interventions in the normal population, children and adolescents and intellectual disabilities.

• Consultations
  – Health professionals on the content of the therapy/treatment,
  – Service users w/ID the accessibility, language and photosymbols of the manual.
• Therapist Manual
  – Information about the application of CBT in ID,
  – Step by step approach to sessions.

• Client worksheets
  – Accessible templates for homework tasks and session worksheets.

• Carer’s Guide
  – How to support an individual who is receiving CBT.

  “Kazantzis and Anderson (2008) found that for people with mild learning disabilities having a carer-giver or support worker in the session with the client helped to provide greater continuity and these people were subsequently better able to assist participants in practicing skills outside the session.”
Examples of worksheets

something happens

what you think

what you do

how you feel

<table>
<thead>
<tr>
<th>day</th>
<th>what happened?</th>
<th>what did I do?</th>
<th>how did I feel?</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
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<td>Su</td>
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<td></td>
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<tr>
<td>good times</td>
<td>one situation I really <strong>enjoyed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>what happened?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>what did I <strong>do</strong>?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>what did I <strong>think</strong>?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>how did I <strong>feel</strong>?</td>
<td></td>
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</tr>
</tbody>
</table>

*Cut out and paste a picture of how you felt*
Cognitive Behaviour Therapy For Learning Disabilities

Acknowledgments

Part I: An Overview of Cognitive Behaviour Therapy For Learning Disabilities

Chapter 1: An Introduction to the Use of CBT in People With Learning Disabilities
Chapter 2: Communicating with People Who Have Learning Disabilities in a Therapeutic Setting

Part II: Protocol for Treating Depression and Anxiety in Learning Disabilities

Chapter 3: The Early Sessions (Sessions 1–4)
Chapter 4: Psychoeducation
Chapter 5: The Middle Sessions (Sessions 5–14)
Chapter 6: Linking Thoughts, Feelings, and Behavior
Chapter 7: Specific Cognitive Techniques
Chapter 8: Specific Behavioural Techniques
Chapter 9: Additional Skills
Chapter 10: The Final Sessions (15–18)

References

Kiran Azam, Dr Marc Serfaty, Professor Michael King, Barry Rydom and Miss Sue Martin.
Feasibility Randomised Controlled Trial
Aim

• Test

- feasibility of delivery of the intervention
- recruitment
- adherence to treatment and treatment fidelity and
- whether treatment the treatment is understood and accepted by carers and service users
Measures

• **Screening:**
  – Mini PAS-ADD (Moss, 2002) for depression (>10) and anxiety (>7).

• **Measures:**
  – Beck Anxiety Inventory Youth (BAI-Y; Beck et al, 2005) – 11-14 yrs.
  – Beck Depression Inventory Youth (BDI-Y; Beck et al, 2005) – 11-14 yrs.
  – Client satisfaction questionnaire (Attkinson, 1982)
  – Manchester Short Assessment of Quality of Life (MANS; Priebe et al, 1999).
  – Client Service Receipt Inventory (CSRI): for health economics.

• All measures administered at baseline, end of treatment (4 months) and six months.

• **Qualitative interviews:** about the experience of therapy.
Participant feedback on therapy process

1101: “I was really reluctant to go because I didn’t find it very useful at all...It made it worse”

1105: “...another good thing was like having the support worker as well...the support worker was very helpful actually”

1105: “the communication was very good...and the positive thing is that some of the things have worked”

1105: “When someone finishes their CBT sessions, like after a month they should have a meeting about how the treatment went...help in ways so that it could improve more things in life...”
dissemination

- [http://www.trialsjournal.co/m/content/12/1/95](http://www.trialsjournal.co/m/content/12/1/95)
Who are the stakeholders in health care systems?

- Top-level decision makers (e.g. government)
- Strategic planners (e.g. health system directors)
- Case-level treatment providers (e.g. GPs)
- Society at large (including the media)
- Patients
- Health services researchers
What public engagement is about

- Working with people whom we do not traditionally talk or listen to
- Placing research at the centre through contact with our local community and other organisations around us
- Starting to think about new ways for public-academic dialogue in intellectual disability
Most funding bodies now require researchers to demonstrate that they have involved service users/carers and other stakeholders in research.
Why it is important to involve service users and carers

- they can participate in research
- they may benefit from research
- they may have good ideas about research and how to collect information
- they may have good ideas about reporting findings
Ways of involving the public

- identifying topics for research
- setting research priorities
- researching projects about service user involvement
- commenting on research
- carrying out research as co-researchers
Examples of public involvement

- be a member of the steering group
- offer an informal opinion
- involve a campaigning organisation
- think about how to find an answer to a question (*systematic review*) as a group
- be a member of a network that comments on research
Activity

• To design a psychological intervention for older people with ID and dementia using the complex interventions framework

  – What type of study design will you use?
  – What will be your outcome measures?
  – What will be the level of patient/public involvement
Centre for Health Services Research in Intellectual Disabilities

Camden learning disabilities service

Islington learning disabilities partnership

working together
Thank you